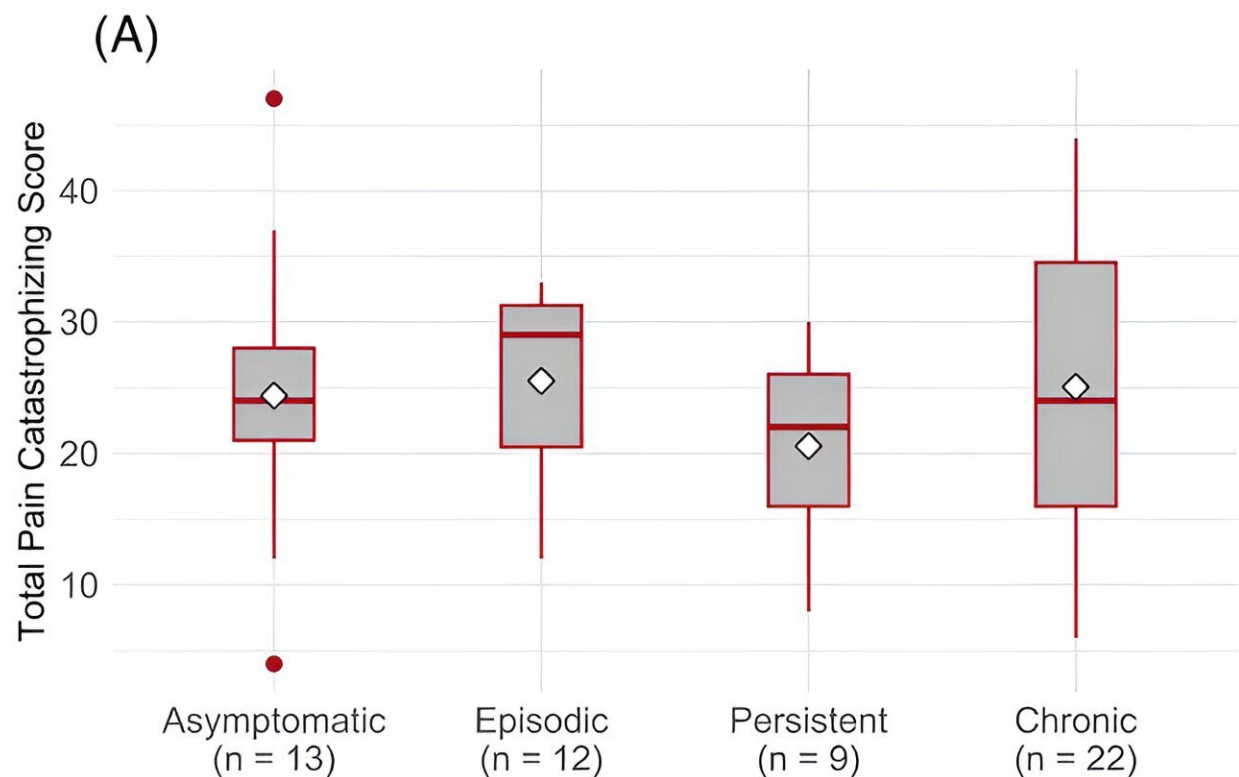


# Pediatric sickle cell disease team uses pain screening to improve care

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Pain catastrophizing boxplots. Panel A includes boxplots of Pain Catastrophizing Scale scores by pain frequency/duration. Panel B includes boxplots of Pain Catastrophizing Scale scores by PPST risk category. Diamonds represent mean values. Credit: *Pediatric Blood & Cancer* (2024). DOI: 10.1002/pbc.30912

A recent study from researchers at University Hospitals (UH) Connor Whole Health and UH Rainbow Babies & Children's Hospital describes a quality improvement project where pain screening procedures were embedded within an outpatient pediatric sickle cell disease (SCD) clinic.

The study examined (1) the feasibility of routine pain screening, (2) the prevalence of various clinical pain presentations, and (3) what integrative health and medicine modalities were preferred by youth aged 8 to 18 with SCD.

The study, entitled "Pain Screening in Youth with Sickle Cell Disease: A Quality Improvement Study," was recently [published](#) in the journal *Pediatric Blood & Cancer*.

Investigators found that the pain screening procedures were feasible when implemented within routine outpatient care. Of the 104 patients screened, 32.7% reported persistent or [chronic pain](#), and 46.2% reported medium or high risk for [persistent symptoms](#) and disability. When asked about their preferences for integrative modalities, patients expressed highest interest in [music therapy](#) (55.6%) and art therapy (51.9%) and preferred in-person (81.5%) over virtual programming (22.2%).

SCD is an inherited disorder that affects red blood cells. In someone who has SCD, [red blood cells](#) become hard, sticky, and C-shaped. When they travel through small blood vessels, they get stuck and clog blood flow. In addition to enduring unpredictable pain crises throughout their lives, many individuals with SCD also suffer from chronic pain.

Unlike other chronic pain conditions, chronic pain in SCD often emerges in adolescence due to the cumulative impact of SCD on bones, blood vessels, and brain function.

"The onset of chronic pain is insidious, and the individual may realize

they have more frequent episodes of pain or that their pain never completely disappears after a vaso-occlusive pain episode like it used to; without realizing, they have developed chronic pain."

"At our center, we seek to manage pain with integrative modalities rather than relying solely on opioids. Early identification of chronic pain through screening increases our chances of successfully managing it with our partners at UH Connor Whole Health," said Amma Owusu-Ansah, MD, Director of the Pediatric Sickle Cell Anemia Center at UH Rainbow Babies and Children's Hospital.

During the study, patients completed questions about the frequency and duration of their pain as well as how their pain affects their physical and mental health. Patients screening positive for (1) persistent or chronic pain or (2) medium or high risk for persistent symptoms and disability were asked to answer additional questions about how pain affects their lives, the thoughts they have when they have pain, and what integrative modalities (e.g., music therapy, acupuncture, massage therapy) they would prefer for managing pain.

To implement the pain screening procedures, the research team developed a comprehensive survey database using Research Electronic Data Capture (REDCap). In addition to streamlining the [screening process](#), this novel REDCap database also auto-scored instruments and created a clinical note for providers to document in the electronic health record. Dennis Vroom, a [medical student](#) at Case Western Reserve University School of Medicine, helped the Pediatric SCD Team implement the process.

Said Vroom, "Pain screening fit well within the clinic workflow, and it gave patients a way to discuss their pain in new ways with their parents, caregivers, and medical providers by asking not just when and how long they were having pain but how it was affecting their daily life and mental

health. This was valuable and made everyone more eager to complete the screening to better understand what the patient was experiencing."

This study builds upon multiple investigations among individuals with SCD led by UH Connor Whole Health. With the support of the Elisabeth Severance Prentiss Foundation, UH Connor Whole Health has recently focused its research efforts on improving care for youth with chronic painful conditions using integrative modalities.

"What this study adds is a systematic process for us to identify patients at high risk for persistent pain symptoms and disability early so that we can intervene and equip adolescents and [young adults](#) with SCD with the skills needed to better manage their pain," said Samuel Rodgers-Melnick, MPH, MT-BC, co-author of the study.

Rodgers-Melnick led a series of studies demonstrating the benefits of integrative modalities such as [massage therapy](#) and music therapy for improving [acute pain](#), [health-related quality of life](#), and the [transition from pediatric to adult care](#) among individuals with SCD.

"UH Connor Whole Health is committed to ensuring our modalities are accessible and tailored to the needs and preferences of people with [sickle cell disease](#). By embedding pain screening procedures within routine care, we are better able to serve this population," said Francoise Adan, MD, Chief Whole Health and Well-being Officer at UH and Director of UH Connor Whole Health.

**More information:** Dennis C. Vroom et al, Pain screening in youth with sickle cell disease: A quality improvement study, *Pediatric Blood & Cancer* (2024). [DOI: 10.1002/pbc.30912](https://doi.org/10.1002/pbc.30912)

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